

Head Injury:
A Family Guide

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SC ▲ DEPARTMENT ▲ OF
DISABILITIES AND SPECIAL NEEDS

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SECTION I

THE CRITICAL PHASE

WHAT IS HEAD INJURY?

A head injury, also called a traumatic brain injury, refers to an injury where there is damage to the brain because of an external blow to the head. A "closed head injury" occurs when there is a blow to the head as in a motor vehicle accident or a fall. In this case, the skull hits a stationary object and the brain, which is inside the skull, turns and twists on its axis (the brain stem), causing localized or widespread damage. Also, the brain, a soft mass surrounded by fluid that allows it to "float," may rebound against the skull, resulting in further damage. There may be a

period of unconsciousness immediately following the trauma, which may last minutes, weeks or months. Due to the twisting and rebounding, the traumatically head-injured patient usually receives damage or bruising to many parts of the brain. This is called diffuse damage.

An "open head injury" is a visible assault to the head and may result from a gunshot wound, an accident or an object going through the skull into the brain. This type of head injury is more likely to damage a specific area of the brain.

Minor head injury may occur with no loss of consciousness and only a dazed feeling or confused state lasting a short time. Although medical care needed may be minimal, persons with minor head injury may still experience symptoms and impairments similar to a traumatic brain injury, but of lesser severity

The definition for moderate to severe head injury is: *an insult to the skull, brain, or its covering, resulting from external trauma, which produces an altered state of consciousness or anatomic, motor, sensory, or cognitive/behavioral deficits.*

HOW DOES THIS INJURY DIFFER FROM OTHER BRAIN INJURIES?

Injury to the brain may also occur as the result of near drowning, heart attack, stroke and infections. This type of injury usually results from lack of oxygen or blood supply to the brain. Although it is traumatic, it is not categorized as a "head injury." This is referred to as "anoxic injury."

WHAT IS BRAIN SWELLING? BRAIN EDEMA?

In response to the trauma, changes occur in the brain which require monitoring to prevent further damage. The brain's size frequently increases after a severe head injury. This is called brain swelling and occurs when there is an increase in the amount of blood to the brain. Later in the illness water may collect in the brain, which is called brain edema. Both brain swelling and brain edema result in excessive pressure in the brain called intracranial pressure (ICP). Around-the-clock monitoring during this time is essential in order that intracranial pressure can be immediately treated. Treatment of brain swelling can be difficult. Very strong medications are administered and in some cases, removal of small amounts of fluids from the brain or surgery may be beneficial.

WHAT IS COMA?

Coma is the prolonged period of unconsciousness immediately following the traumatic head injury. In this sleep-like state, there is no speech, the eyes are usually closed, and there is no response to commands. However, a person in a coma may have a simple reflex in response to touch or pain. The individual may react to pain by groaning or moving but will have no memory of the pain.

It may also appear that the individual is showing signs of hearing and understanding. Often these are also signs of simple reflexes. It may be some time before a patient shows signs of processing

information. However, it is suggested that people talk about or to the individual as if they could hear and understand what is being said.

There are several levels of coma. Professionals measure coma levels by the progression of responsiveness of the head-injured person. In the acute phase of head injury, the Glasgow Coma Scale is used. As the patient improves or stabilizes, the Rancho Los Amigos Scale is used to measure levels of cognitive (understanding and reasoning) thinking.

RANCHO LOS AMIGOS SCALE

The Rancho Levels, as they are called, are an assessment tool or scale that does not require cooperation from the patient. Rather, they are based on observation of the patient as he responds to environmental stimuli. They provide a clear description of the various behavioral stages a head injury victim will experience as he begins to progress through recovery toward rehabilitation.

The Rancho Levels are most useful in the first weeks or months following the injury. The speed at which progression from level to level will occur cannot be predicted. And, just as the rate of progression cannot be predicted, the level of plateau cannot be predetermined.

An understanding of the characteristics of each of the eight Rancho Levels is helpful when families and professionals must deal with the behaviors demonstrated by patients following head injury. The descriptions listed below provide insight into the expected progression during recovery and rehabilitation:

I. No Response

Patient is in a deep sleep and unresponsive to stimuli.

II. Generalized Response

Patient reacts inconsistently and without purpose to stimuli in a nonspecific manner. Responses are limited and often the same, regardless of stimuli presented.

III. Localized Response

Patient responses are specific but inconsistent and are directly related to the type of stimulus presented, such as turning head toward a sound or focusing on a presented object. He may follow simple commands in an inconsistent and delayed manner.

IV. Confused-Agitated

Patient is in a heightened state of activity and severely confused, disoriented, and unaware of present events. Behavior is frequently bizarre and inappropriate to his immediate environment. He is unable to care for himself. If not physically disabled, he may perform automatic motor

activities such as sitting, reaching and walking as part of his agitated state, but not necessarily as a purposeful act.

V. Confused-Inappropriate, Non-Agitated

Patient appears alert and responds to simple commands. More complex commands, however, produce responses that are random and without purpose. The patient may show some agitated behavior; it is in response to external stimuli rather than internal confusion. The patient is easily distracted and generally has difficulty in learning new information. He can manage self-care activities with assistance. His memory is impaired and verbalization is often inappropriate.

VI. Confused-Appropriate

Patient shows goal-directed behavior, but relies on prompting for direction. He can learn former skills, such as activities of daily living, but memory problems interfere with new learning. He has a beginning awareness of self and others.

VII. Automatic Appropriate

Patient goes through daily routine automatically, but performs tasks in a mechanical manner. He has shallow recall of activities and superficial awareness of, but lack of insight to, his condition. He requires at least minimal supervision because judgment, problem solving, and planning skills are impaired.

VIII. Purposeful Appropriate

Patient is alert and oriented, and is able to recall and integrate past and recent events. He can learn new activities and continue in-home and living skills, though deficits in stress tolerance, judgment, abstract reasoning, social, emotional and intellectual capacities may persist.

WHEN WILL WE KNOW THE SEVERITY OF THE HEAD INJURY?

It is difficult to predict the outcome of a head injury in the first hours or days after the accident. There are some general observations that tell us an "on the average" outcome, but no one can specifically predict the effect of a head injury. In general terms the longer the coma lasts, the less likely the individual is to recover fully. The effect of a head injury may be unknown for months or even years. The doctor may answer this question in the term of "wait and see." This is a difficult answer to accept but is often the most accurate, since each head injury is unique and doctors cannot be as precise as might be possible with other types of injuries.

WHAT IS THE BEST WAY TO OBTAIN INFORMATION FROM DOCTORS?

Questions to doctors should be written down. This is a very stressful time for everyone and questions can be easily forgotten. It is advisable to be persistent with questions until they are answered. The family member who asks the question may want to take notes of the answers.

There should be preparation for some unpleasant information and a reminder that there may be no specific answers to some of these questions. It is also good to remember that the recovery process involves a number of specialists who work as a team, and information should be sought from all team members in order to understand the patient's situation.

THERE ARE MANY DIFFERENT PEOPLE CARING FOR THE HEAD-INJURED PERSON. WHO ARE THEY?

Most hospitals use a team system approach in the care of the head-injured person. Family members may become disturbed because the lead doctor is not present at all times. However, each member of this specialized team has a specific and important job to do.

It may be difficult for family members to understand which team member does what and to whom specific questions should be directed. The following is a list of professionals who may be part of the team during various stages of the recovery process:

- **Neurosurgeon**
Physician specialist trained to care for all varieties of brain problems and perform brain surgery as needed. This person is primarily concerned with coordinating the medical treatment of the head-injured and deciding whether or not there is a need for surgical treatment.
- **Neurologist**
Physician specialist concerned with treating disorders of the brain, nerves and muscles.
- **Rehabilitation Nurses**
Specially trained to care for the patient depending on the stage of treatment. They provide and coordinate all patient care, act as liaison to other team members and are often a patient advocate.
- **Respiratory Therapist**
Concerned with helping the patient breathe adequately as a means of preventing further complications and/or infections. If the patient is on a respirator, the respiratory therapist is responsible for maintaining the equipment. If the patient is unable to cough up secretions, the respiratory therapist may assist by lowering the head, tapping the back and suctioning the patient.
- **Physiatrist**
Physician primarily concerned with evaluating the traumatic head injury's impact on the functioning of the patient's body (not just the brain) and helping the patient to overcome any disability that has occurred.
- **Physical Therapist**
Concerned with helping the patient regain maximum functioning of body movement or to prevent further deterioration of physical function in the unconscious patient. This is done initially by moving the arms and legs (called range of motion) and thereby exercising unused muscles.

- **Occupational Therapist**
Concerned with helping patients with activities of daily living (ADL) and with recovering functions which help them return to gainful employment and maximum independence.
- **Speech Therapist**
Concerned with helping the patient return to normal or alternative patterns of communication.
- **Clinical Psychologist/Clinical Neuropsychologist**
Concerned with evaluating the mental functions of the patient's brain and planning training programs to help the patient's brain return to normal functioning as quickly as possible. He/she will assist with emotional and behavioral problems.

Depending on the extent of injuries the patient has sustained it is not uncommon for the admitting physician to consult with other physicians with special skills, such as infectious disease control; ear, nose and throat; orthopedic; ophthalmology; oral surgery; etc.

WHAT IS ALL THE EQUIPMENT ATTACHED TO THE PATIENT?

The brain is the coordinator of the rest of the body's functions. Head injury may result in the brain not performing these functions as well as necessary. It is therefore essential that it be given as much help as possible from the medical staff and equipment in order that all bodily functions are maintained.

This section lists and describes, in alphabetical order, the equipment most commonly found surrounding a patient with head injury and how this equipment is used by the medical staff in helping the patient. Each patient may not have all of this equipment. A diagram below shows the location of the equipment on the patient.

- **Arterial line**
A very thin tube (catheter) is inserted into one of the patient's arteries (usually in the arm) to allow direct measurement of the blood pressure and to measure the concentration of oxygen and carbon dioxide in the blood. The arterial line is attached to a monitor.
- **Brain stem-evoked response equipment**
Auditory brain stem responses evoked by stimulating the brain stem with painless sound waves using headphones. These sound waves are received by the brain, and a machine is used to test whether the brain stem has received the signals. The quality of the brain stem's functioning in a comatose patient is thought to be an important indicator of the degree and site of brain injury. Since this test requires very specialized and expensive equipment, it is not available in all hospitals. A more common test is the EEG (Electroencephalogram).
- **Catheter (kath-a-ter)**
A flexible plastic tube of varying sizes with multiple uses.

- **Central venous pressure (CVP) line**
A very thin tube (catheter) inserted into one of the patient's veins to allow direct measurement of the venous blood pressure (the pressure of the blood as it returns to the heart). CVP lines are inserted into veins in either the patient's arm or the chest just below the shoulder, or occasionally on the side of the neck. The CVP catheter is connected to a monitor.
- **Chest tubes**
Tubes inserted into the patient's chest between the lung and ribs to allow fluid and air to drain from the area surrounding the lungs. Removing this fluid and air from around the lungs allows them to more fully expand. An accumulation of fluid and air in the lung cavity can cause the lung to collapse. Chest tubes drain into a large plastic container near the foot of the patient's bed. The patient may have one or more of these tubes in place.
- **Electrocardiogram (EKG)**
Usually three small, round electrode pads located on the patient's chest to monitor heart rate and rhythm. These are connected to a monitor and used routinely in the intensive care unit.
- **Endotracheal tube (ET tube)**
A tube that serves as an artificial airway inserted through the patient's mouth or nose. It passes through the throat and into the air passages to help breathing. To do this it must also pass through the patient's vocal cords. The patient will be unable to speak as long as the endotracheal tube is in place. It is this tube that connects the respirator to the patient.
- **Eye tape**
Tape used to close the patient's eyes. It is important that the eyes be kept moist. We do this naturally when we blink our eyes. This reflex is lost in the patient who is unresponsive but has open eyes. To protect the eyes and to prevent them from drying out, eye drops may be put into the eyes and eye tapes may be used to close them.
- **Foley catheter**
This is a tube (catheter) inserted into the urinary bladder for drainage of urine. The urine drains through the tube into a plastic bag hanging low by the foot of the bed.
- **Intracranial pressure (ICP) monitor**
A monitoring device to determine the pressure within the brain. It consists of a small tube (catheter) attached to the patient's skull by either a ventriculostomy, subarachnoid bolt or screw, and is then connected to a transducer.
- **Intravenous (IV) board**
A simple wooden or plastic board usually attached with tape to the patient's forearm. It prevents bending and dislocation of the intravenous, arterial or CVP lines.

HOW LONG WILL IT TAKE TO RECOVER?

Due to the uncertainty accompanying brain injury, it is difficult to predict a level of recovery. However, to speak in general terms, the recovery from brain injury happens in stages. The first stage includes intensive, lifesaving medical and technical procedures which occur in an acute care facility immediately following the trauma. After the acute care stage, the challenge of recovery then shifts to focus on the remaining stages of: physical, occupational, and neuropsychological restoration.

The rate of recovery is most rapid during the initial weeks of the head injury or after the person awakens from the coma. It is important that the period of rapid recovery does not mislead both the family and treatment staff to predict continued rapid, perhaps complete, recovery. Unfortunately, when there is a slowdown of recovery after this stage, it can be very difficult for families. However, individuals progress at their own rate of recovery. It is important to note that a slowdown in progress does not mean an end to recovery. Continued gains in function have been reported even several years after the injury.

There are many factors that will affect the level of recovery after head injury, such as: age at injury; severity and part of the brain affected by the injury; length of time in coma; pre-existing personality characteristics; quality of pre-hospital (paramedic/ EMS) and hospital care; speed of entry into head injury rehabilitation program; the nature of the support network; and involvement of family.

WHAT CAN THE FAMILY DO TO HELP?

After the initial crisis, a family should try to return to a routine that is as normal as possible. Family members should stay in touch with friends and stay involved in activities they enjoy. It is important to stay in touch with the outside world.

Family members should ask the medical staff for ways they can be involved in the daily care of the patient. Loving care from family members is important in the recovery process. It is also a productive way to spend time with the patient as well as a learning process for family members.

Families are encouraged to learn about head injuries so they will be better able to help the head-injured person recover to the fullest extent possible. Families should inquire as to the availability of reading material on head injury through the hospital, doctor or social worker. Families may also receive helpful information from the SC Department of Disabilities and Special Needs and local head injury support groups.

When a head injury occurs, the family, as well as the patient, can be traumatized. The family is placed under extreme emotional, physical and financial stress. The "Family and Friends" section in this guide addresses these difficulties and also offers suggestions for coping with the changes this injury brings to the family structure.

WHAT ARE THE VARIOUS PROCEDURES BEING USED WITH THE PATIENT?

During the rehabilitation process, rehabilitation specialists may be involved with the care and treatment of the patient. Some rehabilitation programs may use a multi-disciplinary team. The team may include the physician, pathologist, neuropsychologist, recreation therapist and others. Goals are established by the team based on experience and the patient's abilities.

WILL THE BRAIN HEAL ITSELF?

Brain tissue that is injured can recover over a short time period. Evidence shows, however, that once brain cells are dead or destroyed, new brain cells cannot grow. The recovery process of the patient continues to take place even though new brain cells are not growing. The recovery is thought to happen when other parts of the brain take over the function of the destroyed brain tissue. In extensive damage to the brain, it is less likely that the remaining brain can assume the function of the destroyed areas. In this case the patient must learn how to compensate for this loss through other methods involving adaptations in the environment or in his/her own behavior.

HOW WILL WE KNOW WHEN THE CRITICAL PHASE IS ENDING?

In the early stages of recovery when the critical phase is ending, there will be signs that the patient is coming out of coma. Evidence of wakefulness and increasing consciousness will occur during this period. The recovery of consciousness is a gradual process and is not just a matter of waking up as people often imagine.

The patient begins to open his/her eyes and obey simple commands on an inconsistent basis. Often there will be confusion, disturbed behavior and memory loss even after the patient is fully alert. After a head injury, the patient will generally have no memory of the event.

SECTION II

REHABILITATION

WHAT IS REHABILITATION? WHEN AND WHERE SHOULD IT BEGIN?

Rehabilitation is the process of helping the patient achieve maximum functional potential. As a patient nears discharge from the receiving hospital (acute care hospital), the family should seek the advice of the physician or the social services director for information to plan the rehabilitation. Rehabilitation services may be delivered in different settings, such as specialized head injury rehabilitation centers, inpatient rehabilitation hospitals, outpatient rehabilitation hospitals, and/or various services provided by professionals in a home setting.

WHAT HAPPENS IN A REHABILITATION PROGRAM?

The course of rehabilitation following acute care varies with the needs of the head-injured person. The patient should be thoroughly evaluated to determine the brain's function, so that a rehabilitation program can be developed for each patient's special needs. If there is a physical need, it is valuable to continue in physical and occupational therapy. It is important to achieve success in physical capability at the same time the brain is continuing in its slow healing process.

Speech and language therapy is an important part of the rehabilitation process. Head injury almost always disrupts communication skills. Speech therapy will focus on problems with expressing and understanding language. Language problems are common and are often long lasting challenges for the head-injured person.

Cognitive rehabilitation is another major aspect of rehabilitation and involves a variety of techniques and programs focused on thinking and reasoning skills. In general this would include working on organization of thought and time, sequencing, problem solving, decision making strategies, and improving mental speed and capability.

Psychotherapy is beneficial for persons with head injury as their lives have changed significantly from this experience. A period of assistance may be needed for family members as well, in order that they learn to accept change and develop realistic expectations for the head-injured person. Psychotherapy will help everyone understand behaviors of the head-injured person on the basis of physiological damage and not merely as a sign of his/her poor adjustment to the experience.

Other forms of medical attention and rehabilitation needed, such as music, equestrian and recreational therapies will be determined by the uniqueness of each head injury

Educational and vocational rehabilitation may be required for reintegration into an educational program and for job training.

Individuals will have their own rate of recovery with periods where progress may appear to slow and then pick up again as new challenges are presented.

HOW ARE THE PROBLEMS EVALUATED?

A number of professionals will be involved in evaluating the brain's function. Professionals will be evaluating in their specialized area. Diagnostic equipment is available to help detect skull fractures and other damage to the brain. Clinical tests and procedures such as EEGs, brain scans and personality assessment are also used in evaluation. It is desirable that the various professionals operate as a team, if possible, so that their evaluations can be integrated into a cohesive program. See glossary of neurological tests and procedures.

A neuropsychological assessment may be one of the evaluations conducted. This is a comprehensive procedure that provides a detailed description of the brain-behavior relationships that are the consequences of brain trauma. A wide range of psychological tests, interviews, observations and procedures are used in order that mental functions of the brain can be measured. A typical neuropsychological test may be spaced over several days in consideration of the patient's level of endurance. This assessment helps the professional and the family understand the nature and extent of the brain injury. This information is used to develop an individualized rehabilitation program to aid the patient toward maximum recovery.

WHAT TYPES OF REHABILITATION FACILITIES ARE AVAILABLE?

The following is a list of major categories used to describe the array of rehabilitation facilities that are available. These descriptions should serve only as a guide as it is up to the individual and family to investigate specific programs and facilities to determine their suitability.

- ▲ **ACUTE REHABILITATION** - Facility to treat patients as soon as they become medically stable. This program often exists within an acute care hospital, as a unit of a general rehabilitation center and/or as a free standing facility for the rehabilitation of traumatic head injury.
- ▲ **INPATIENT/OUTPATIENT REHABILITATION** - Facility for a more seriously head-injured person who requires extended, intensive and comprehensive therapies in a structured program, having all the elements found in an acute rehabilitation center. Focus will be on cognitive and memory retraining, speech therapy, daily living skills, restructuring lost social behavior, and continued physical therapies.
- ▲ **TRANSITIONAL LIVING** - The goal of the transitional program is to prepare individuals for maximum independence, to teach necessary skills for community interaction and to work on vocational training. Programs may be in a variety of settings such as small group homes or special educational institutions.
- ▲ **LONG-TERM REHABILITATION** - Facility to provide long term rehabilitation in a non residential-like setting as opposed to a hospital setting. This is a program for the patient who is making slow improvements and needs long-term intensive therapy. These facilities are generally not for permanent placement.

- ▲ **DAY TREATMENT SERVICES** - Program created to improve functional skills including physical and occupational therapies, cognitive therapy, social adjustment, pre-vocational training, independent living skills and so on. These programs are community-based and may be offered through resources in the local area.
- ▲ **RESPITE PROGRAM** - Opportunity for the patient and family to take a short "vacation-like" break from each other. Respite programs are becoming recognized as an important element in long-term rehabilitation.

WHAT ARE SOME GUIDELINES FOR SELECTING A FACILITY?

- ▲ Always try to obtain the names of at least three programs to consider for your family member.
- ▲ Location should be just one of the many factors families consider in regard to selecting a head injury rehabilitation program. If a nearby program is not familiar with traumatic head injury, it may be better to travel a distance to ensure an appropriate program.
- ▲ Request a worksheet, "What to Look for in Selecting a Rehabilitation Facility," from the National Head Injury Foundation, before visiting facilities. This outline will provide a checklist and appropriate questions to assist with the decision-making process. Write down answers to your questions during interviews to enable you to compare information from the different programs.
- ▲ It is most important that the prospective program treatment team all have expertise in head injury rehabilitation. There should be a team approach to planning and treatment.
- ▲ Ask for the names of families of individuals who have recently been patients in the program. Ask the families' satisfaction with the program. Did it meet their expectations? What were they told prior to admission? What did they find the program to be? What would they do differently?
- ▲ Tour the facilities. Look for a clean environment with a caring, conscientious staff and adequate space for treatment teams to provide treatment.
- ▲ Be sure there are regularly scheduled staffings, including all disciplines, family members and significant others.
- ▲ Ask if the head injury program is accredited by a nationally recognized accrediting body.
- ▲ Finally, the decision you arrive at must be based on your own individual opinions. They will continue to be the most important criteria in the rehabilitation of your loved one.

WHERE CAN FAMILIES FIND RESOURCE INFORMATION AND MEDICAL ASSISTANCE?

There are several agencies you can turn to for guidance. You should gather as much knowledge as possible about the services available in your community to allow you to make a decision that will best meet the patient's needs. The following two listings are good places to begin.

▲ A Local Head Injury Support Groups

A source of assistance for families and friends of people with injuries are local head injury support groups— information, advocacy and educational organizations that provide support for persons with head injury and their families. Groups are comprised of family members, head injury survivors, professionals and friends concerned about the unique problems of persons with head injuries.

▲ SC Department of Disabilities and Special Needs

In 1993, South Carolina established, under a state statute, a Head and Spinal Cord Injury Division. This program was established to assist residents of South Carolina in obtaining rehabilitative services necessary for maximum levels of independent functioning and community reintegration.

To find out more about this program you should consult your local telephone directory under "County, Disabilities and Special Needs Board"; or write or call:

SC Department of Disabilities and Special Needs
PO Box 4706
Columbia SC 29240
(803) 898-9600
V / TTY: (803) 898-9600
Fax: (803) 898-9653
Toll Free: 1-888-DSN-INFO (376-4636)

After rehabilitation, you may find that the following organizations in your community may be helpful:

Local school system
Goodwill Industries
Community hospitals
United Cerebral Palsy
Life Abilities (formerly Easter Seal Society)
Local support groups
Local parks and recreation agencies that have programs for special groups :

SECTION III

FAMILY AND FRIENDS

WHAT REACTIONS MIGHT BE EXPECTED FROM FAMILY MEMBERS?

The family as well as the head-injured person is traumatized when a severe head injury occurs. The person they depended on and loved is no longer the same. The family is placed under extreme stress to assume unaccustomed roles, which may include caregiving, becoming breadwinners, and advocating on behalf of the injured person.

This, along with the possible changes in physical functioning and personality suffered by the person with a head injury, may place an unusual burden of stress on members of the family. It is not uncommon for family members to occasionally react in ways that others do not understand. Some family members may choose to immerse themselves in efforts to help the injured family member while other family members may be emotionally unable to cope with the situation and need to distance themselves from trauma.

After a person suffers a severe head injury, the family reaction will be ever-changing as their expectations change. Over the course of the hospitalization, rehabilitation and reintegration into the community, they sense the "loss" of the person they once knew and loved and begin to know and love the person who may be altered somewhat as a result of the trauma. Mourning the loss of that person is important to emotional well-being.

Most people go through a grieving process which is a natural and normal part of accepting what has happened. These stages include:

- ▲ Denial: "No, this couldn't have happened to us..."
- ▲ Anger and frustration: Family members may feel anger toward anyone who could be seen as the cause of the injury. They may feel victimized and frequently develop a hostile attitude directed toward those professionals who are working with the injured person and cannot "fix" the problem.
- ▲ Depression and withdrawal: Family members may lack the motivation to care for themselves, physically and emotionally. They may feel isolated when friends, who were very supportive initially, become less involved as the process of restoration of the injured person drags on. With few social contacts, the family may become more hopeless and less functional.
- ▲ Acceptance: The family, over an indefinite period of time, should begin to accept the changes that have occurred in their loved one and begin to heal. The process of mourning the loss of the person may confuse the issue of acceptance, but ultimately both the family and the person with the head injury must accept what cannot be changed and learn to get

on with a life of the highest quality possible.

HOW CAN FAMILY MEMBERS MINIMIZE STRESS?

The following is a list of guidelines to help family members minimize their stress. Family members should:

- ▲ Maintain contact with friends and activities that they enjoy.
- ▲ Work out a rotating visitation schedule with other family members. This will allow needed time for themselves.
- ▲ Be aware of the needs of other family members. They need to know that they have not been forgotten.
- ▲ Ask and accept help from others. This assistance could be such activities as running an errand, mowing the lawn or bringing in a meal.
- ▲ Express feelings and do not try to keep everything inside. Talk to other family members, the social worker, a minister, a case manager, or anyone with whom they feel comfortable.

WHAT IS THE FAMILY'S ROLE IN RECOVERY?

The patient's family should be involved in the recovery, rehabilitation and readjustment process to the greatest extent possible. The primary role of the family and/or significant others is one of advocacy on behalf of the person with the head injury.

No family is prepared for this unfamiliar task which might include a commitment of time and effort that is often difficult to maintain for many reasons, the least of which is economic. They may be overwhelmed with uncertainties about the nature and extent of the injury, the need to understand how the injury will affect the person and the need to know how to plan for the future.

One of the first tasks the family can perform is that of family historian, to describe the injured person for the benefit of the health care professionals so that they can include this information in their interpretation of what is occurring with the patient. After all, the family knows this person better than anyone else.

Members of the family should ask the staff for guidance in working with the patient. This might include asking for information about equipment and procedures being used, determining how the family could enhance the therapy which is being delivered by the professionals, and requesting direction to other departments of the hospital that provide assistance (e.g., social services department, family education coordinator, etc.).

Throughout the recovery, which may extend over an undetermined length of time, family members can be supportive even when they are unable to be at the patient's bedside. Their

advocacy efforts can play a major role in securing benefits to which the patient is entitled. These benefits may involve securing financial, insurance and employment information necessary in determining eligibility for various benefits and programs. It might include contacting the authorities and collecting information from the accident scene, in the event of a possible litigation; gathering information about traumatic head injury to assist with the advocacy; and joining with other families of persons with head injuries for mutual understanding and support.

Family members must realize that even the best medical care is incomplete without the loving concern and encouragement that comes from the patient's family. There may be years of hard work before returning to pre-injury activity and possibly physical or mental disability that is never fully recovered. Families of persons with head injury must adjust to the fact that the recovery process is a slow "labor of love" for everyone involved. The patient must reach a certain level of accomplishment in each recovery stage before the next treatment will be beneficial. During this painstaking process it is natural for anyone to become impatient. Family members must not feel guilty about these feelings, but must come to understand that a task cannot go any faster than the injured brain. Simple tasks must be mastered before the more complicated mental and physical skills can be re-learned. The family members' role is to be as understanding as possible while still tending to their own needs and to support the individual's progress with praise and acceptance.

The role of the family will change with an extended rehabilitation process and the family members will need to adjust and adapt to these changes. The more severe the injury the more drastic these changes will be. All affected persons play changing roles and many will experience periods of isolation, loneliness, grief, guilt and helplessness. In time and with the support of those who care, all survivors and their families can find laughter and good times again.

HOW WILL THE FAMILY BE AFFECTED?

Families of individuals with head injuries must realize the inescapable effects on and changes within the family structure. If the head-injured person is the income provider, there will likely be changes in marriage/family relationships, income, economic stability and social status. One or more family members may be forced to assume the role of provider. When the head-injured person is the homemaker, role revision again takes place. Duties and responsibilities must be shared by other family members.

When the injury is severe, parents of a head-injured child are faced with loss of dreams, in addition to the eventual realization that life-long care may be necessary. They must tackle the task of considering how to provide vocational, emotional and financial support for their child for a lifetime. Family and friends need to work together to help the head-injured patient toward maximum recovery and to reduce stress on the people carrying the greatest personal burden.

This may be a time of loneliness and isolation for the family. Family members spend hours at the bedside with the patient in a strange city, or even in their hometown. The worry and fatigue that families experience will leave little time to interact with others. Also, many people in the community are unfamiliar with head injury and this often leads to gradual withdrawal of contact

and support to the family on their part. Families often need support from those who understand the pain and loss they are suffering.

Family members' ability to cope is very important and often professional support and guidance can be helpful. Also, support groups are available throughout the state, depending on the type of injury, for family members who wish to talk and to interact with others who have gone through similar experiences.

Information about support groups and resources to help families cope may be obtained through the local Disabilities and Special Needs Boards.

SOME LONG-TERM CONSEQUENCES OF TRAUMATIC HEAD INJURY

COGNITIVE

- memory loss (short- and long-term)
- problems in arousal, attention and concentration
- problems in initiating, planning and completing action
- problems in judgment
- difficulty in recognizing one's cognitive deficits/limits
- spatial disorientation (problems with perception, direction etc.)
- slowness of thought processes
- slowness and/or difficulty with speech

PHYSICAL

- hemiparesis
- seizures
- spasticity
- visual impairments
- reduced endurance
- loss of taste

PSYCHOSOCIAL

- anxiety and depression
- emotional lability
- denial
- inappropriate behaviors (impulsiveness and lack of inhibition)
- egocentricity
- agitation/outburst (short tempered, irritable)
- sexual dysfunction
- loss of social networking, feeling of isolation

SUGGESTIONS FOR UNDERSTANDING AND LIVING WITH A PERSON WHO IS HEAD-INJURED

Most head-injured persons need some degree of help and structuring throughout their lives. At first this structure will be provided through a hospital or rehabilitation facility. As the rehabilitation process progresses, it is hoped that the head-injured person can provide more of the daily structuring themselves.

It may difficult to reach a balance between what head-injured persons can do for themselves and what is needed from others. The following is a list of general principles offered to help the person with a head injury achieve his/her goal of independence.

- ▲ Keep surroundings familiar and consistent.
- ▲ Establish and maintain a daily routine of regularly scheduled meals and activities.
- ▲ Encourage break periods whenever frustration or fatigue appears, or often enough to prevent them from occurring.
- ▲ Use memory aids such as reminder notes, labels, calendars and wall charts.
- ▲ Include the head-injured person in conversation and family affairs.
- ▲ Treat the head-injured person as an adult with respect to his/her likes and dislikes about such things as food, clothing, music and recreation. It is important to note that these likes and dislikes may have changed.
- ▲ Let the head-injured person answer for himself/herself and have some control over his/her life.
- ▲ Provide specific choices from which to choose rather than requesting an open-ended decision. For example, "Would you like to watch TV or read a book?" rather than "What would you like to do?"
- ▲ Keep activities or tasks relatively simple, using one- or two-step directions and repeating them frequently.
- ▲ Don't compare or expect behavior to be as it was before the injury.
- ▲ Give praise for desired behavior and brief, to-the-point criticism for undesirable behavior. This is a difficult balance to achieve.

SUGGESTIONS FOR THE PERSON WHO IS HEAD-INJURED

Accepting realistic, needed help from others is required while striving for increased independence. To achieve a maximum level of recovery depends on a committed and persistent effort from everyone, especially the head-injured person. The following is a list of guidelines that may make recovery easier for the head-injured person.

- ▲ Keep a detailed plan of activities you do and intend to do.
- ▲ Ask questions, only after you ask yourself first. Asking too many questions will make you dependent and will not encourage your critical thinking.
- ▲ Use NO alcohol or drugs. These substances will only dull the brain and are dangerous when used with needed medication.
- ▲ Do not use negative thinking, such as "I can't." Be willing to try new things.
- ▲ Keep a daily schedule. This will help establish and maintain schedules, as well as offer predictability and consistency.
- ▲ Write things down. This will help you to remember and help to reinforce learning skills. As you hear it, write it and see it.
- ▲ Set realistic goals. Review these goals periodically.
- ▲ Do not be afraid to ask for and/or accept help from others.

AREAS OF THE BRAIN

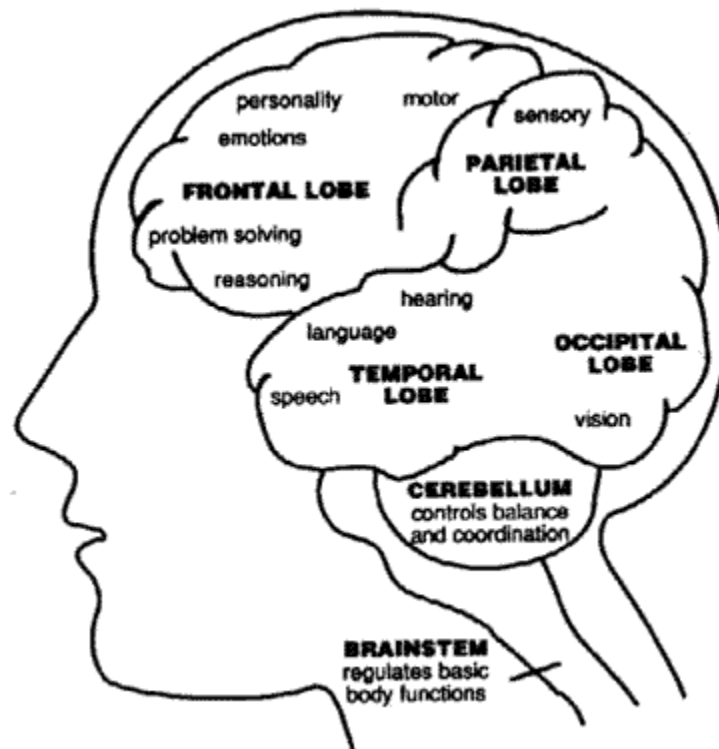
The brain is the control center for all of the body's actions and functions. It receives messages and interprets them. The brain responds to messages by enabling a person to perform the vital processes of breathing and moving, as well as thinking, judgment and emotional reactions.

A fundamental awareness of the brain's structure may help in understanding what happens to the brain during head injury.

The brain is comprised of three areas:

- ▲ **Brain Stem** - The brain stem connects the brain to the spinal cord. Structures in the brain stem control consciousness, arousal and vital functions such as breathing, blood pressure and pulse rate.
- ▲ **Cerebellum** - The cerebellum controls muscle, coordination and balance.
- ▲ **Cortex** - The cortex is the largest area of the brain and is where most thinking functions occur. The cortex is divided into four lobes. Each lobe has a specialized function as shown in the diagram on page 32. In addition, the cortex is divided into two halves (hemispheres). The dominant hemisphere, usually the left, controls verbal functions such as speaking, writing, reading and calculating. The right hemisphere controls functions that are more visual in nature such as memory, drawing or copying.

No two traumatic head injuries are the same, just as no two individuals are identical. This is because different areas of the brain are affected with each injury and the effects are multiple. Because of these multiple effects and the fact that the damage is often widespread, traumatic brain injury differs from other types of brain damage such as stroke, brain tumor, drug or alcohol-induced problems and degenerative disease.



GLOSSARY OF TERMS

ABSTRACT REASONING: process of generalizing from concrete examples and experiences to larger, broader principles.

ACALCULIA: dysfunction or inability to perform mathematical operations, recognize numbers or count.

ACUITY: keenness of sensation.

AGNOSIA: loss of ability to recognize familiar people, places and objects.

AGRAPHIA: loss of ability to express thoughts in writing.

ALEXIA: inability to read or recognize words.

ANOXIA: a lack of oxygen which can cause damage to the brain. This can result when blood flow is reduced (such as in electrocution).

ANOMIA: dysfunction or inability to name objects or recall individual names.

ANTEROGRADE AMNESIA: loss of memory for events and periods of time following an injury or traumatic event.

APATHY: decrease in motivation, initiation, interest in life and growth; indifference.

APHASIA: loss in ability to speak coherent ideas or understand spoken language.

APRAXIA: loss of ability to carry out habitual movement or acts that were previously automatic.

ASTEREOGNOSIS: inability to recognize objects or shapes by feeling them.

ASYMMETRY: discrepancy in function or appearance between sides or organs.

ATAXIA: dysfunction in motor coordination and balance.

ATTENTION: ability for sustaining focus on task for a period of time to allow for coding and storing of information in memory.

BRAIN STEM: the lower portion of the brain which connects it to the spinal column. The brain stem coordinates the body's vital functions (breathing, blood pressure and pulse).

CEREBELLUM: the portion of the brain which is located below the cortex. The cerebellum is concerned with coordinating movements. **COGNITION:** the process of thinking, understanding and reasoning.

COMA: unconsciousness lasting for more than a brief period of time. A state of unconsciousness where the person cannot be aroused and/or does not respond.

CONTRA-COUP: when the brain sustains sufficient force, causing it to bounce against the opposite side of the skull, thereby causing injury to both the site of impact and the part of the brain opposite the impact.

CORTEX: the largest portion of the brain consisting of two cerebral hemispheres which are connected by a band of tissue (the corpus callosum). This is the area where most thinking and cognitive functioning takes place. It is sometimes referred to as the cerebrum.

DIFFUSE: brain damage which covers many areas of the brain rather than one specific location. Diffuse damage is common in closed head injuries due to the brain moving about and tissue being torn, stretched or bruised.

DIPLOPIA: seeing two images of a single object (double vision).

DISINHIBITION: the inability to control or inhibit impulses and emotions.

DISORIENTATION: disturbance in recognition of person, place and/or time and day.

DYSARTHRIA: disruption or dysfunction in speech articulation.

EDEMA: collection of fluid (water) in the brain causing swelling.

EMOTIONAL LABILITY: intense fluctuations of emotions in response to experiences.

FRONTAL LOBE: the area of the brain located at the front on both the left and right sides. This area plays a role in controlling emotions, motivation, social skills, expressive language and inhibition of impulses. The motor strip controlling movement and motor integration runs along the posterior (back) of the frontal lobe.

FRUSTRATION TOLERANCE: the amount and degree of frustration; the point at which a person can no longer control his/her anger and responds by yelling, throwing things or displaying aggressive behavior.

GLASGOW COMA SCALE: a scale of severity of injury developed by B. Jennett, M.D., and C. Teasdale, M.D. This scale relates the level of consciousness with three factors: motor responses, eye opening and verbal responses.

HEMATOMA: when an area of tissue swells and fills with blood.

HEMIPARESIS: weakness of one side of the body (or part of it) due to injury to motor areas of the brain.

HEMISPHERIC ASYMMETRY: differences in the types of functions for which the two sides of the brain are responsible. (For example, the left side is usually associated with verbal functions, while the right side is associated with spatial abilities).

HEMORRHAGE: bleeding that occurs following trauma. Bleeding may occur within the brain when blood vessels in the skull or the brain are damaged.

INFLEXIBILITY: rigidity in thinking stereotyping; difficulty in recognizing alternative possibilities.

JUDGMENT: ability for resolving dilemmas and approaching problems; includes values, morals and interpretation with respect to interaction.

LIMBIC SYSTEM: a set of structures (usually considered part of the temporal lobe) which play an important role in memory, attention, emotions and behavior.

MEMORY: stored recollections about experiences, events, feelings, dates, etc., from the recent and distant past.

OCCIPITAL LOBE: the posterior (back) part of each side of the brain, involved in perceiving and understanding visual information.

PARIETAL LOBE: the upper middle lobe of each side of the brain involved in perceiving and understanding sensations and closely linked to speech fluency and writing.

PERSEVERATION: over-reliance on or repetition of a specific response or behavior to different tasks.

PREMORBID: a term to describe the patient's condition before the injury or illness.

POST-TRAUMATIC AMNESIA: loss in memory for events related to a traumatic event and the period immediately following the trauma.

PROBLEM-SOLVING: skills for employing reasoning, judgment and discernment in resolving problems.

PROXIMAL INSTABILITY: impaired strength or muscle tone of the trunk, shoulder girdle or hip girdle. This can cause poor posture, abnormal movement of the limbs, inability to sit up and inability to hold one's head up.

QUADRIPARESIS: a weakness which involves all four limbs.

RANCHO LOS AMIGOS SCALE: an assessment tool that provides a description of the various behavioral stages a head injury victim will experience as he/she progresses through rehabilitation.

RETROGRADE AMNESIA: loss of memory for events and periods of time before an injury or accident.

SPASTICITY: an abnormal increase in muscle tone, causing the muscles to resist being stretched. A patient with spasticity may look "curled up," with his arms held close to his chest, or he may appear very stiff.

SPONTANEOUS RECOVERY: the recovery which takes place spontaneously as the brain heals. This type of recovery occurs with or without rehabilitation and it is often difficult to know how much improvement is spontaneous and how much is due to rehabilitative interventions. It occurs early in the recovery process.

TACTILE DEFENSIVENESS: being overly sensitive to touch; withdrawing, crying, yelling or striking out when touched.

TEMPORAL LOBE: the lower middle part of each side of the brain involved in receiving information from the auditory system and involved in memory.

UNILATERAL: pertaining only to one side.

UNILATERAL NEGLECT: unawareness of or inattention to one side of the body or the space or events occurring on one side of the body.

VENTRICLES: four cavities in the brain which are filled with cerebrospinal fluid, serving as a cushion when the brain is impacted.

VESTIBULAR: awareness of movement involving the head. Disorders of the vestibular system can lead to a lack of awareness of movement, a lack of awareness of direction of movement or hypersensitivity to movement.

VISUAL FIELD DEFICIT: not visually perceiving information in a specific area of the visual field.

PROXIMAL INSTABILITY: impaired strength or muscle tone of the trunk, shoulder girdle or hip girdle. This can cause poor posture, abnormal movement of the limbs, inability to sit up and inability to hold one's head up.

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GLOSSARY OF MEDICINES WHICH MAY BE USED FOR PERSONS WITH HEAD INJURY

antibiotics: seriously injured people are susceptible to many kinds of infection because of their injuries and the many lines and tubes inserted into their bodies. Several kind of antibiotics may be given. Most antibiotics are given through an intravenous catheter (IV) whereas others may be placed on the skin or into the nasogastric tube. Occasionally antibiotics must be given through a ventriculostomy catheter directly into the ventricles of the brain.

Decadron (dexametasone): one of the steroids given to lessen brain swelling.

Dilantin (phenytoin): an anti-seizure drug which is usually given to prevent seizures in seriously head-injured persons. dopamine: a potent drug used to increase blood pressure in critically ill, head-injured persons.

Lasix (furosemide): this drug assists the body in eliminating water. It may be used to treat increased intracranial pressure, too much water in the lungs or sluggish kidneys.

Maalox: a medicine usually given by the nasogastric (NC) tube to help prevent the stomach ulcers (stress ulcers) which head- injured people are prone to develop.

mannitol: a medicine used to remove water from the brain and thereby lower intracranial pressure (ICP). The mannitol and water are then eliminated by the kidneys.

morphine (MS): a strong sedative which is also an excellent pain reliever. Head-injured people who receive this narcotic in the intensive care unit almost never become addicted to it because of this treatment. Morphine is often used to sedate head-injured people so that they do not "fight" the ventilator.

Pavulon (pancuronium bromide) and curare: drugs which temporarily paralyze muscles. These medicines are used to prevent the head-injured person from "fighting" the ventilator to control intracranial pressure (ICP) and to relax the patient while performing medical procedures.

pentobarbital (Nembutal): a strong sedative which has been used to help control intracranial pressure (ICP). When used in this way, pentobarbital acts as an anesthetic which places the head-injured person in a deeper coma. Since the physical examination can no longer tell how the patient is doing, monitors must be used for this purpose.

phenobarbital: an anti-seizure drug used to prevent seizures in head-injured persons, especially children. Phenobarbital may occasionally be used like pentobarbital to control intracranial pressure (ICP).

steroids of which **Decadron** is an example: potent drugs which are used to lessen brain swelling.

Tagamet (cimetidine): a drug used to help prevent stomach ulcers.

Valium (diazepam): a sedative tranquilizer which is very effective at quickly stopping repetitive seizures when given intravenously.

GLOSSARY OF NEUROLOGICAL TESTS AND PROCEDURES

BEAM (BRAIN ELECTRICAL ACTIVITY MAPPING): computerized analysis of background EEC activity, much more sensitive than conventional EEC, which is especially helpful in identifying abnormalities of early dementia or suspected brain damage from head injury.

BRAIN STEM-EVOKED RESPONSES: brain stem response to a specific stimulus recorded electronically.

CT SCAN (COMPUTERIZED TOMOGRAPHY): computerized x-ray taken at different levels of the brain which yields a three-dimensional representation of the physical shape of the brain.

ELECTROCARDIOGRAM (ECO OR EKG): electrical measure of heart activity and heartbeat that is produced on a chart recording.

ELECTROENCEPHALOGRAM (EEG): an evaluation of electrical activity of the brain.

MRI SCAN (MAGNETIC RESONANCE IMAGING): an instrument that develops images from biochemical operations of the brain by using a magnetic field.

NEUROLOGICAL EXAMINATION: an assessment of gross nerve functioning via reflexes and reactions; performed by a neurologist or neurosurgeon.

NEUROPSYCHOLOGICAL EVALUATION: specialized tests and measures that provide a detailed description of the brain, behavior relationships that are consequences of brain trauma.

PET SCAN (POSITRON EMISSION TOMOGRAPHY): an instrument that records chemical activity in specific regions of the brain.

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